Patient Satisfaction in Specialized versus Nonspecialized Adult Sickle Cell Care Centers: The PiSCES Study

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Background: Sickle cell disease (SCD) patients can receive their ambulatory care from either SCD specialists (caregivers with sickle cell-only clinics) or nonspecialized care centers. Patient satisfaction, an important factor that may influence compliance and outcome, can differ between the two groups because of the perceived quality of care, outcomes or practice style.

Methods: We administered a patient satisfaction survey to 308 participants in an SCD prospective cohort study. Of the 308 patients, 133 (43.2%) received the majority of their SCD care at specialized centers, 152 (49.3%) received their care from nonspecialized centers and 26 (7.5) did not provide information. The satisfaction surveys measured general satisfaction (GS), technical quality (TQ), interpersonal manner (IM), communication (CM), financial aspects (FA), time spent with doctor (TA), and accessibility and convenience (AC). Patients reported their levels of satisfaction using a five-point Likert scale. We compared unadjusted group means, as well as means adjusted for potential confounders such as marital status, on patient satisfaction between specialized and nonspecialized centers.

Results: SCD patients who received their care from specialized centers had significantly higher mean satisfaction scores, compared to those who received their care from nonspecialized centers: GS 4.00(±0.93) vs. 3.66 (± 01.16, p=0.0326), TQ 3.98 (± 0.77) vs. 3.65 (± 0.91, p=0.0058), AC 3.83 (± 0.79) vs. 3.51 (± 1.02 , p=0.0142) , FA 3.88 (± 0.96) vs. 3.49 (± 1.25, p=0.0120). There were no statistically significant group differences in IM, TA and CM.

Conclusion: SCD patients who received most of their SCD care from specialized centers had somewhat higher satisfaction scores in some areas when compared with patients who received their care from nonspecialized centers.

Key words: sickle cell anemia ■ quality of care

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INTRODUCTION

Sickle cell disease is a set of genetic abnormalities primarily affecting patients of African and Mediterranean descent. It is caused by a substitution of valine for glutamic acid in the sixth position of the beta globin chain.[1-4] The physiologic effect is a hemolytic anemia accompanied by vaso-occlusion that can cause acute and chronic pain and lead to organ damage. Vaso-occlusive episodes cause pain and chronic organ failure, predict early mortality, and are responsible for the majority of medical contacts in this population.[5] Sickle cell disease is responsible for a significant portion of U.S. healthcare costs and healthcare use.[6] A conservative estimate of charges resulting from hospital use is $36 million per year. Another $14.4 million per year results from emergency department (ED) use. A liberal charge estimate is $108 million per year resulting from hospital use.[7]

SCD patients represent a challenging patient population to clinical practice, especially for adult physicians. Recurrent acute pain episodes are usually managed by the ED. Pediatricians, both hematologists and generalists, manage most care of children, often as part of a holistic care system. Federal and state requirements and medical care guidelines call for universal newborn screening and identification of new SCD patients,[8,9] and caregivers must provide prophylaxis with pneumococ-

cal vaccine[10-13] during the childhood years. Adult care is more fragmented and has limited data on quality of care. Emerging reports have shown that specialty care is well warranted. Although a recent cross-sectional study found no clear pattern of improved use of medical care services in relation to proximity of residence to a CSCC, this cohort was not large enough to detect small differences in death rates.[14] In contrast, a statewide longitudinal study showed that comprehensive sickle cell care improved SCD mortality.[15] Newer data suggest that SCD children also need screening and prophylactic transfusion to prevent stroke and subsequent mortality

However, no parallel care system exists for adults with SCD. Anecdotally, patients report that they are eventually—sometimes abruptly—discharged from the pediatrician, and then managed by often unfamiliar EDs and primary care physicians with limited exposure to SCD, little training in chronic pain management, and very few (often no) other SCD patients in their panels. Perhaps as a result of this unfamiliarity and lack of training, some physicians might label SCD patients seeking relief of their pain as drug seekers or drug abusers.[16,17] In addition, access to care for these patients is often limited by their socioeconomic status. SCD patients' educational level and income resemble that of U.S. blacks, but SCD unemployment rates are higher, and SCD males' personal income levels are lower.[18] Not surprisingly, SCD patients are frequently dissatisfied with the care they receive from EDs and their primary physicians.[17] When compared to other chronic disorders such as asthma, their satisfaction with care is significantly lower.[19] They avoid going to busy EDs where they perceive that they are rudely or slowly treated.[20] Disputes may occur between patients and ED staff about SCD patient behaviors, thereby raising staff concerns about analgesic misuse.[21]

There is limited data on the quality of care received by the few adults with SCD who receive their care in specialized care centers. No studies to date have measured the satisfaction of these patients. We hypothesized that patient satisfaction would be higher in this group as a result of higher perceived quality of care, outcomes, or practice style.

METHODS

Study Population

A cohort of 308 patients living primarily in the central and tidewater regions of Virginia were enrolled in a prospective study to evaluate the association of sickle cell pain, crises and healthcare use on a daily basis. The baseline data collection at enrollment included information on health status, quality of life, medical history and other information. In addition, patients completed a satisfaction survey related to the quality of their healthcare.

Recruitment

The patients were recruited as part of the Pain in Sickle Cell Epidemiology Study (PiSCES). The details of the recruitment strategies have been previously described.[22] Briefly, patients are recruited statewide through a variety of networks including health fairs, referrals, targeted mailings and established clinics. Specialized centers are defined as established centers with well-structured sickle cell management programs where patients receive their sickle cell care. The patients were identified by their sickle cell physicians. Patients who were identified as eligible were scheduled for an enrollment visit. A trained research cocoordinator administered the short-form Patient Satisfaction Questionnaire-18 (PSQ-18) at this visit.

Table 1. Description of cohort

	Specialized Center	Nonspecialized Center	P Value
Age (Mean ± SD)	32.8 ± 11.0	33.9 ± 11.5	0.4130
Gender			0.9612
Male	52 (39.1)	59 (38.8)	
Females	81 (60.9)	93 (61.2)	
Education			0.1703
< High school	19 (14.3)	21 (14.0)	
High school	58 (43.6)	49 (32.7)	
Some college	40 (30.1)	63 (42.0)	
College	16 (12.0)	17 (11.3)	
Marital Status			0.0473
Married	29 (21.8)	32 (21.2)	
Never married	92 (69.2)	90 (59.6)	
Separated/divorced/widowed	12 (9.0)	20 (19.2)	
Genotype*			0.4888
SS	92 (71.3)	97 (68.3)	
SC	28 (21.7)	38 (26.8)	
Other	9 (7.0)	7 (4.9)	

Analytic Variables

The PSQ-18 is a short-form version of the 80-item PSQ developed by Ware in 1976 that retains many characteristics of its full-length counterpart. The PSQ subscales show good internal consistency and reliability. The PSQ-18 was appropriate for use in our situation where brevity was important because of the other survey instruments being used during the enrollment visit. The PSQ-18 takes approximately three to four minutes to complete. The PSQ-18 is validated and publicly available.[23] Patients reported level of satisfaction using a five-point Likert scale, in which strongly agree, agree, uncertain, disagree and strongly disagree correlated with numbers 1–5, respectively. The satisfaction surveys measured general satisfaction (GS), technical quality (TQ), interpersonal manner (IM), communication (CM), financial aspects (FA), time spent with doctor (TA), and accessibility and convenience (AC).

Statistical Analysis

Demographic and clinical variables were compared between patients who attended specialized and nonspecialized centers using t tests (continuous variables) and Chi-squared tests (categorical variables). We compared group means on patient satisfaction using analysis of covariance, controlling for any demographic or clinical variables found to differ between groups. The analysis used SAS® 8.2 for UNIX software (SAS Institute, Cary, NC). The study was approved by the hospital's institutional review board (IRB).

RESULTS

Patient demographics are consistent with other studies of this type (Table 1). Of the 308 patients, 133 (43.2%) received the majority of their SCD care at specialized centers, 152 (49.3%) received their care from nonspecialized centers, and 26 (7.5%) did not provide information.

There were no significant differences in demographics and SCD severity (as measured by genotype) between the patients who were seen at specialty centers and those who were not, except for marital status. More people being seen at specialty centers were never married and fewer were divorced, separated or widowed ($p<0.05$). This may be driven by the larger number of widowed, divorced and separated persons in the nonspecialized centers. The impact or the reason for this difference is unknown and the numbers are too small to do further analysis. When marital status was controlled for, we noted no differences in the satisfaction scores and therefore estimates were left unchanged. The average age of the cohort was 34 years, 61% were female, and the overwhelming majority finished high school (86%) The majority of patients in this study (70%) have hemoglobin-SS disease (Hgb SS). In this cohort, the patients with Hgb SS, the most severe genotype, do not appear to seek care at specialty centers more than those with other genotypes.

The PSQ-18 demonstrated that SCD patients who received their care from specialized centers had significantly higher mean satisfaction scores compared to patients who received their care from nonspecialized centers in the GA, TQ, AC and FA categories (Table 2). Differences in satisfaction with CM were marginal ($p=0.073$). There were no statistically significant group differences in satisfaction related to IM and TA.

DISCUSSION

SCD is a chronic disorder in which patient dissatisfaction can affect compliance or treatment utilization. Our cohort of patients who received care from specialized centers had significantly higher scores on the PSQ-18 when compared with sickle cell patients who received their care from nonspecialized centers in four of seven categories. The results might be reflective of the differences in structure and resources that a specialized center can provide. The familiarity of the overall socioeconomic and medical challenges that SCD patients might encounter and the development of mechanisms and support groups allow for increased resource availability to the patients. There were no significant differences in time spent with doctor, interpersonal manner, or communication, suggesting that the superior satisfaction in patients treated at specialized centers is not

Table 2. Comparison of satisfaction for patients cared for at specialized centers versus nonspecialized centers: PSQ-18 results

	Specialized Center Mean (SD*)	Nonspecialized Center Mean (SD)	P Value**
General satisfaction	4.00 (0.93)	3.66 (1.16)	0.0326
Technical quality	3.98 (0.77)	3.65 (0.91)	0.0058
Accessibility and convenience	3.83 (0.79)	3.51 (1.02)	0.0142
Communication	4.10 (0.93)	3.84 (1.04)	0.0730
Time spent with doctor	3.80 (1.03)	3.59 (1.11)	0.1500
Financial aspects	3.88 (0.96)	3.49 (1.25)	0.0120
Interpersonal manner	4.12 (0.88)	4.12 (0.92)	0.8945

* SD: standard deviation; ** Controlling for marital status

a result of nonspecific doctor–patient relationship differences. The most statistically significant difference was in fact in patient satisfaction with technical quality of care. In essence, a specialized center might provide the advantage of increased resources, as well as physicians who are more comfortable in treating complex patients with sickle cell disease.

SCD in the adult population is widely believed to be fragmented and to have a poor transition of pediatric to adult patient management services. A significant portion of care for adults is provided by practitioners with limited numbers of patients and, as a result, a lack of comprehensive resources specifically designed for SCD.

Comprehensive care centers are currently used in a variety of chronic disease conditions such as diabetes, cancer, hypertension and sickle cell disease. These specialized centers allow for a multidisciplinary management approach. The higher volume of patients managed by these centers also has the potential to improve outcomes because these practitioners and their facilities will develop greater expertise, which has shown to improve outcomes in other populations. High-volume hospitals for some conditions and surgical procedures have been shown to potentially reduce hospital mortality.[24,25] Several studies in the oncology literature show remarkably consistent evidence that the more experience doctors or healthcare systems have with a procedure, the better the results.[26] There is even some evidence that outcomes can be improved with standardized care and clinical practice guidelines in cancer.[27] De Berardis et al. examined the long-lasting debate on the role of generalists and specialists in the management of diabetes. They found that the quality of care was improved by managing patients in a diabetes outpatient clinic with a physician whose specialty was diabetes.[28]

A key component to providing comprehensive care is to improve the quality of care as well as to ensure or improve the satisfaction of these patients. There are numerous studies to evaluate the care given in various hospital departments and outpatient clinics.[29-32] These are often part of quality assurance or quality improvement programs.

Vichinsky first reported the effects of comprehensive sickle cell centers and comprehensive care on morbidity and mortality in 1991.[32] Yang, in a 1995 public health report, noted that patients enrolled in a comprehensive sickle cell program accounted for less of the total healthcare costs and had lower use of the ED and inpatient wards.[33] The increasing emergence of comprehensive sickle cell centers as well as the recent passage of legislature to fund national sickle cell centers further supports this. Comprehensive care improves the quality of life of people affected by SCD and reduces the number as well as the length of hospital admissions.[34]

The data are limited for assessing the impact of comprehensive sickle centers and are nonexistent for patient satisfaction between specialized and nonspecialized centers. In our cohort, we begin to address differences that might exist between specialists and generalists, specifically looking at patient satisfaction. The data demonstrate higher reported patient satisfaction scores in the specialized centers. The use of specialists or specialized care centers to administer care not only might improve objective measures of quality of care but also might improve less frequently measured outcomes such as patient satisfaction.

Further evaluation in terms of measuring outcomes between these two groups must be done to determine whether differences in outcome are identified. Although our results demonstrate a statistically significant difference, the correlation to clinical significance was not addressed in this study. The minimum clinically significant difference in this population of patients has not previously been identified but would be an important component to address in a future validation study. Future studies and follow-up analysis of our data are required in order to better inform us on the clinical significance of these differences. Larger studies involving greater numbers of specialized centers with multiple clinical outcome measures are required in order to determine whether these results are generalizable. As in other chronic diseases, assessment of treatment outcomes should include not only objective measures such as mortality and physical morbidity but also measures such as patient satisfaction and quality of life. With the possibility of improved quality of care, higher patient satisfaction further demonstrates the need for improved adult SCD patient management and specifically through specialized centers.

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